

# Advance Care Planning Information Dementia

### Advance Care Planning

Advance Care Planning is the process of thinking and talking about future medical decisions if you had a sudden event, like a car accident or illness, and could not make your own decisions. The best time to make these decisions is when you can choose for yourself.

### **Health Care Agent**

A Health Care Agent is the person you choose to make medical decisions on your behalf if you are unable to make your own decisions. Discussing and sharing your wishes with your Health Care Agent is important.

## Advance Directive for Health Care

An Advance Directive is a written plan that names your Health Care Agent and allows you to provide instructions for health care treatments based upon your values and what is important to you.

For more information about Advance Care Planning or for help creating an Advance Directive for Health Care, contact your health care team or Honoring Choices <sup>®</sup> Idaho.

HonoringChoicesIdaho.org 208-947-4285 info@honoringchoicesidaho.org

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Advance Care Planning involves important real life conversations to reflect on, discuss, and plan for a time when you cannot make your own health care decisions. Cognitive impairment and dementia are illnesses that will affect your ability to think, express thoughts, and make decisions. Participating in advance care planning early and throughout the illness is an especially important way to prepare for future healthcare decisions. Discussing your goals and values, and choosing a person who will make future decisions on your behalf, allows your loved ones and health care providers to honor and support your wishes if the illness leaves you unable to express them.

Dementia is a terminal illness, which means there is no cure. You may have questions and uncertainty about how much and how quickly the illness will affect you. You can find reliable and respected information about what to expect from:

- Alzheimer's Association (www.alz.org / 1-800-272-3900)
- Your doctor and other members of your health care team

Given all that is known about dementia and the likelihood of decline, it is important to communicate your goals and preferences for future care with those close to you and your health care team.

#### How do I start?

Take this one step at a time. You don't have to do this all at once!

- Choose the person who will make health care decisions if you are not able.
   This person is called your Health Care Agent. (See more information on the other side).
- Tell your loved ones what is important to you. (See more information on the other side).

You can find help on how to start the conversation at:

- Honoring Choices<sup>®</sup> Idaho (www.honoringchoicesidaho.org)
- The Conversation Project Conversation Starter Kit for Families and
   Loved Ones of People with Alzheimer's Disease/Dementia
   (Ask your health care team for a copy, download a copy at www.theconversationproject.org, or contact Honoring Choices<sup>®</sup> Idaho.)
- Discuss your goals and values with your Health Care Agent, others close to you, and your health care team.
- Write down your preferences in an Advance Directive for Health Care and ask your health care team to document your preferences in your medical record.
- Ask your Health Care Agent and health care team to keep discussing your goals and preferences with you as the illness evolves.

See other side for additional information.

#### **Early Stage Dementia:**

"Early-Stage" refers to people, no matter their age, who are diagnosed with Alzheimer's disease or related illnesses and are in the *beginning* stages of the disease. In this early stage people can participate in daily activities and in a give-and-take dialogue. People with early stage dementia includes people under the age of 65 that develop dementia ("younger-onset") and are in the early stages of the disease.

### Younger Onset Alzheimer's:

Younger-onset Alzheimer's, also known as early-onset Alzheimer's, refers to individuals younger than age 65 who have a diagnosis of Alzheimer's disease. Younger onset does not refer to a specific stage of the disease. People with younger-onset dementia can be in the early, middle or late stages of the illness.

### Where should I keep my completed Advance Directive?

Keep your signed and completed original Advance Directive in an easily accessible place where you keep other important documents. Give copies to:

- Your Health Care Agent(s)
- Family members or other loved ones who are likely to be involved in your health care
- Your primary care provider or health care team
- Your local hospital
- Idaho Secretary of State Health Care Directive Registry (<a href="https://sos.idaho.gov/hcdr/index.html">https://sos.idaho.gov/hcdr/index.html</a>)

Where can I find the Honoring Choices® Idaho Advance Directive? Visit the Honoring Choices® Idaho website (www.honoringchoicesidaho.org)to download a copy or to request a copy be mailed to you contact Honoring Choices® Idaho at (208) 947-4285 or info@honoringchoicesidaho.org

### Who should I choose as my Health Care Agent?

Your Health Care Agent is the person you choose and authorize to make health care decisions on your behalf if you cannot communicate or make decisions for yourself. To choose the best person to be your Health Care Agent, ask:

- Who is able and willing to serve this role?
- Who will honor my wishes even if they do not agree with them?
- Who can make important health care decisions on my behalf during difficult or stressful situations?
- Who will stand up for me even if others disagree?
- Who will be involved in my day-to-day life and can tell my health care team about changes in my condition?
- Who is likely to be available in case of an emergency?

### What types of decisions can I make? What should I talk about with my loved ones?

### My values:

- What is most important to me as I think about how I want to live? What matters to me at the end-of-life? What brings me joy and comfort?
- How much do I want to know about my illness?
- What cultural, religious, or spiritual beliefs, if any, might help me choose the care I want or don't want?
- What fears or concerns do I have related to my illness?
- What abilities are so important to me that I can't imagine living without them?

### My treatment goals:

- How involved do I want my Health Care Agent in my care decisions? Do I
  want my Health Care Agent to do exactly as I have said in conversations
  or written in an advance directive or do I want them to have some flexibility
  in making future care decisions on my behalf?
- Is it more important to live as long as possible *or* is quality of life more important than quantity? What treatments will support my goals?
- Do I want everything possible done to keep me alive and for how long?
   For instance, if I can no longer feed myself, do I want nutrition and/or hydration given artificially or offered by hand? If I have trouble breathing on my own, do I want a machine or medication to help me breathe?
- Where do I prefer to spend my last days?

### How do I use the Advance Directive to document my preferences related to dementia?

Use Page 2 of the 'Durable Power of Attorney for Healthcare' to describe your preferences for care and decisions you'd like your Health Care Agent to make on your behalf. Think about describing the three most important things you want your Health Care Agent to understand about your preferences and goals for care at the end of your life.

#### When is my Advance Directive used?

You control your own medical care. If you become unable to choose or communicate your wishes, your health care team will follow the instructions as described in your Advance Directive and as your Health Care Agent directs. Be sure to give copies of your Advance Directive to your Health Care Agent and to your health care team.